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People with Disabilities Still at Risk in Congregate Care Settings

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RESEARCH BRIEF

People with Disabilities Still at Risk in Congregate Care Settings

August 2021

RTC:Rural

Research & Training Center
on Disability in Rural Communities

KEY FINDINGS:

- **This report provides an analysis of data to better understand where cases and deaths are rising in nursing homes as of August 8 2021. We hope this analysis can help support local community planning and networking among rural partners to improve outcomes.**
- **COVID-19 cases among residents and staff are on the rise in nursing homes with the steepest increases in urban areas and in the South and Midwest.**
- **Disabled people are disproportionately overrepresented in the resident populations of unsafe congregate settings, such as nursing homes.**
- **Vaccination rates across both residents and staff in nursing homes have stagnated.**
- **Policy priorities should be set by people with disabilities and disability-led organizations to promote community-based efforts such as transition and relocation from unsafe congregate settings into the community.**

Introduction

COVID-19 cases among residents and staff of long-term care facilities are once again on the rise. The emergence of the more infectious [delta variant](#) and the [persistently low rates of vaccinations among nursing home staff](#) are threatening the lives of millions who live in nursing homes and congregate care settings across the country. Since May of 2020, the Centers for Disease Control and Prevention (CDC) has been collecting and providing [public data](#) via the National Healthcare Safety Network (NHSN) Long Term Care Facility (LTCF) COVID-19 Module: Surveillance Reporting Pathways and COVID-19 Vaccinations on the impact of the pandemic in CMS funded facilities across the country (CDC, 2021 the [Centers for Medicare and Medicaid Services \(CMS\)](#) reported). As of August 8, 2021 there have been 133,736 resident deaths and 2,004 staff deaths reported in CMS funded nursing homes.

Several factors are at play in the tragically high rates of infection, hospitalization, and death within congregate care settings, including the environment, residents, and staff. First, within congregate living facilities, people reside closely together and share staff, centralized ventilation systems, dining, living and bathing spaces. Infection can spread rapidly in these environments, where consequences are severe. This is particularly true of respiratory infections like COVID-19, where the virus is able to move quickly through crowded spaces. Second, congregate care settings have admitted patients who are COVID-19 positive to relieve pressure from hospitals.

Congregate Care Residents

People with disabilities are disproportionately represented in congregate living settings. Figure 1 illustrates this disparity and highlights one of the ways that disabled people have been unduly impacted by the pandemic and under recognized in data collection and analysis. People with disabilities constitute entire populations in nursing homes, adult group homes, psychiatric hospitals, residential treatment centers, and residential schools for people with disabilities. In addition, people with disabilities are disproportionately represented in other settings such as emergency and transitional shelters for the unhoused, and across all types of correctional facilities (i.e. prisons and jails).

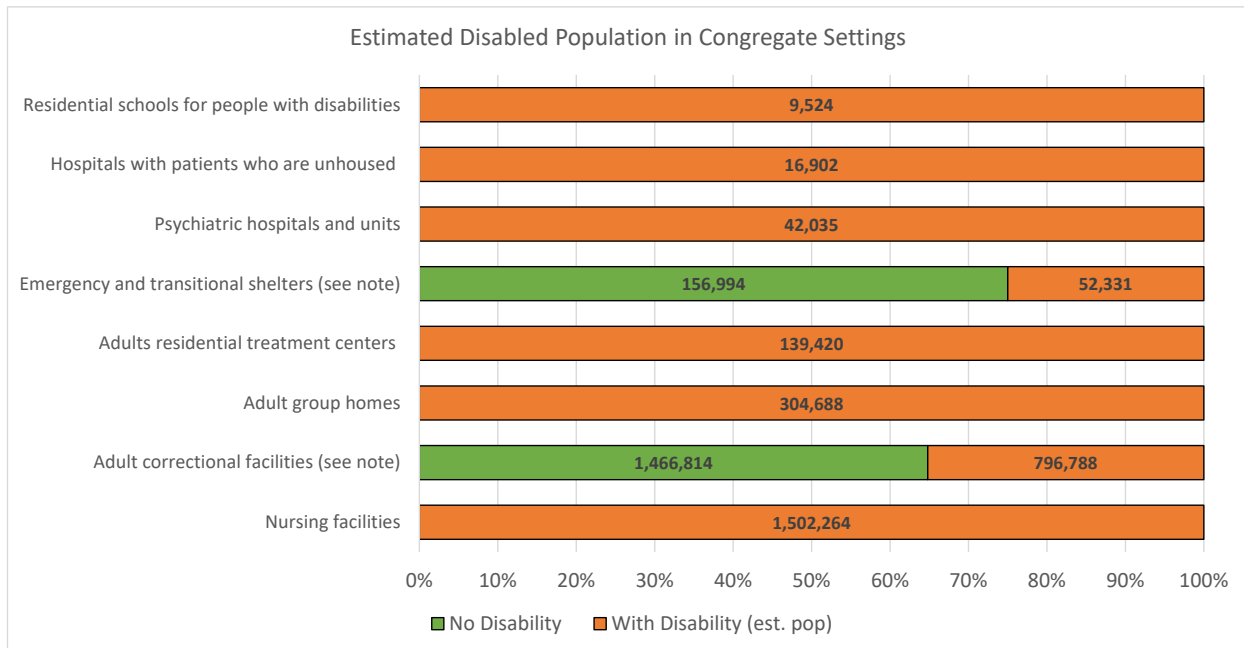


Figure 1: Disabled People in Congregate Settings

* Note: Data for counts of populations in congregate settings from US Census, 2010.
Estimates of disabled people in correctional facilities from Vallas, 2016.
Estimates on people with disabilities in homeless shelters from USICH, 2018.

Congregate Care Staff

Third, staff working in congregate care settings, particularly in rural communities are vaccinated at alarmingly low rates considering the environments and residents they serve. Figure 2 shows the average vaccination rates of healthcare staff in CMS nursing homes across the nation and by [metropolitan, micropolitan, and non-core counties](#). Figure 3 shows vaccination trend rates among CMS nursing facility staff and residents for US geographic regions from May through August. While most residents are vaccinated across regions, staff vaccination rates are particularly low in noncore, Midwest, and Southern locations, posing significant risk to those they serve.

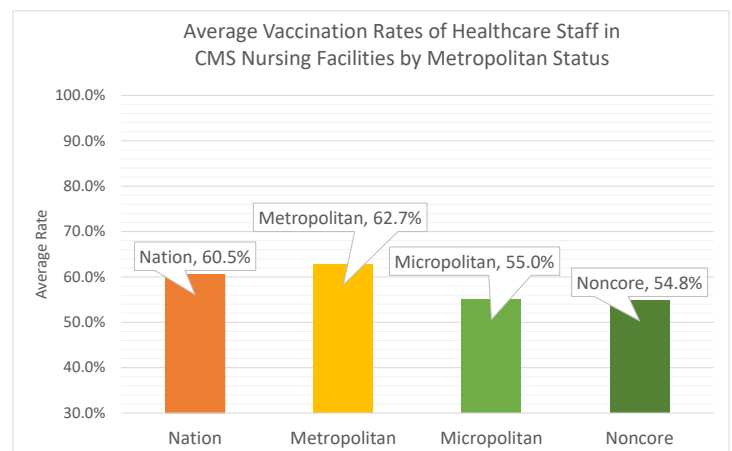


Figure 2: Average Vaccination Rates of Healthcare Staff

Average Staff and Resident Vaccination Rates in CMS Nursing Facilities by Region, 2021

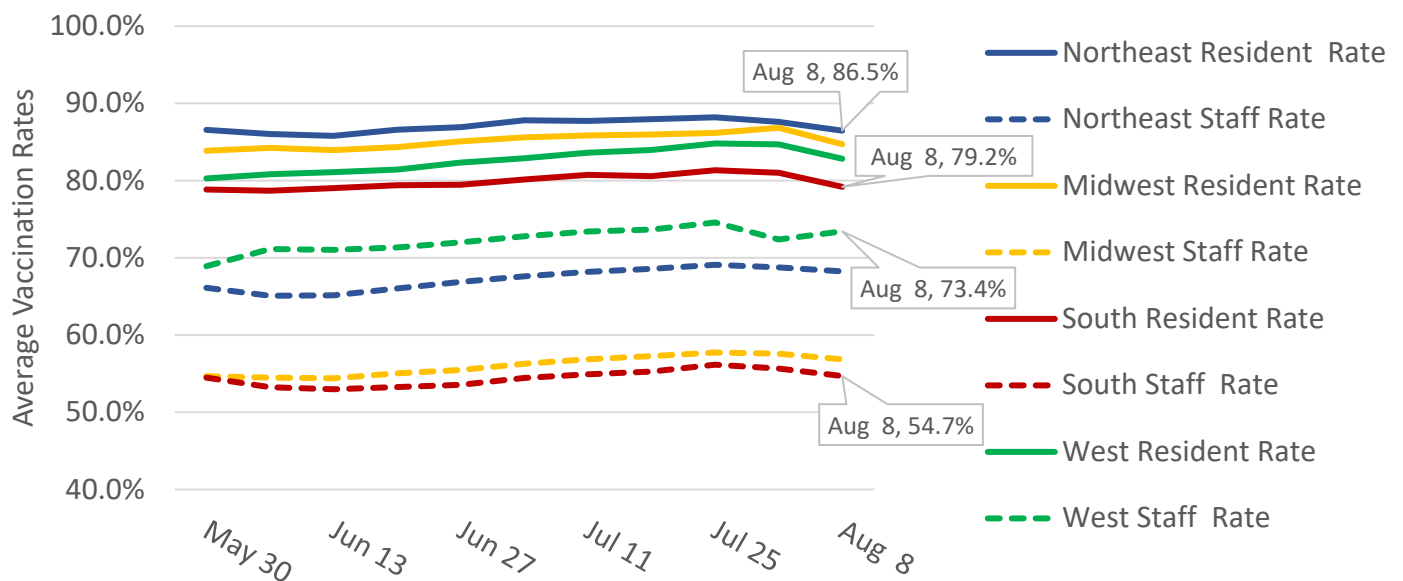


Figure 3: Average Staff and Resident Vaccination Rates by Region

* Note: These are average rates across a region and therefore do not reflect the current vaccination rates of specific facilities. For information on specific facility rates visit the [CMS Nursing Home Data dashboard](#).

CMS Nursing Home Facilities

In general, COVID-19 data collection across different types of congregate care facilities has been limited and disjointed, leaving advocates, emergency management and public health professionals, researchers, and policy makers unsure about the full extent of the pandemic's impact on residents and workers. Nursing homes, however, are one type of congregate care setting where data collection has been somewhat more robust, though [significant gaps](#) and challenges in [nursing home data reporting remain](#).

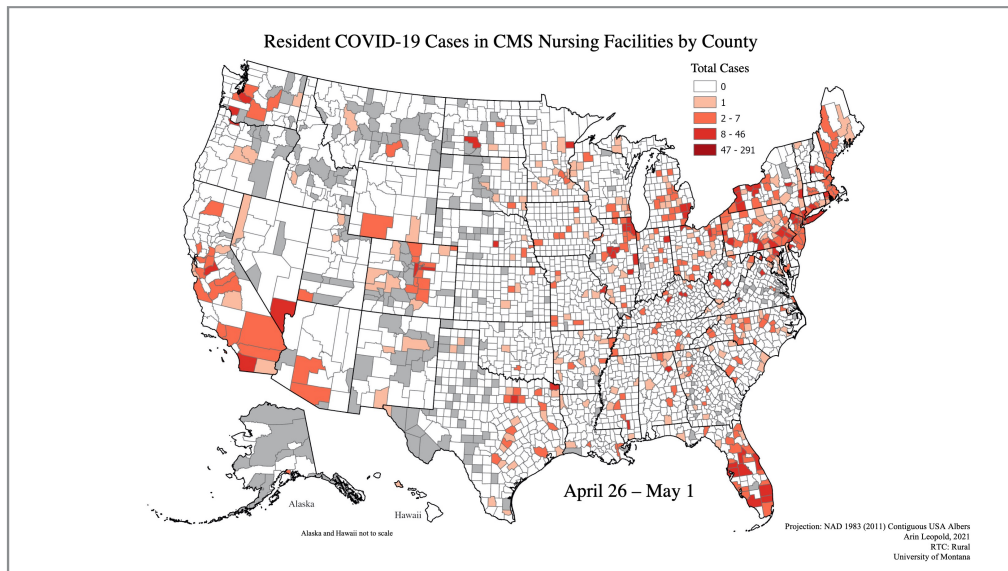
Since May of 2020, the Centers for Medicare and Medicaid Services (CMS) has been collecting and providing [public data](#) on the impact of the pandemic in its facilities across the country. In June of 2021, CMS required additional data reporting on vaccination rates among residents and staff. This report provides an analysis of CMS data to better understand where cases and deaths are rising in nursing homes as the delta variant has swept the nation. We hope these analyses can help support local community planning and networking among rural partners to improve outcomes.



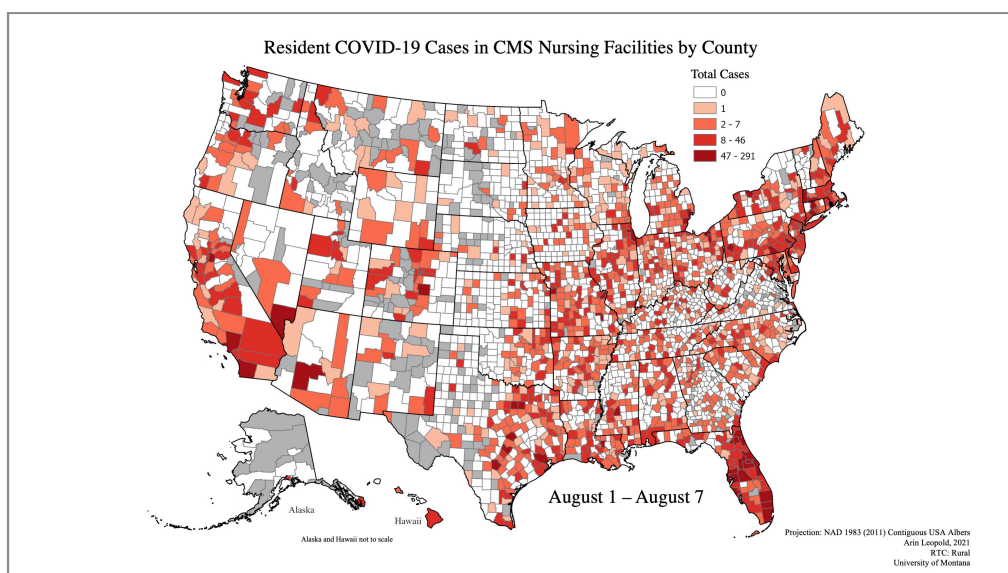
Delta Variant Takes Hold

The resurgence of COVID-19 cases can be traced to the new Delta variant. The following two maps compare the number of resident COVID-19 cases in May 2021 and August 2021 as the delta variant took hold in the U.S. As the CMS data shows, the increase in cases is substantial, even though residents are vaccinated at higher rates.

These two maps illustrate the change in COVID-19 cases in CMS Nursing homes, by county, over a period of 14 weeks from May 2 (Map 1) to August 8 (Map 2). The first map representing the week ending May 2 shows a majority of counties across the U.S. shaded white or pink, indicating zero or 1 resident cases. In urban areas across the country, states like Florida, Pennsylvania, New York, Illinois, California and Washington had clusters of counties with outbreaks of up to 46 resident cases; these counties are shaded in red.



The second map illustrates how cases across the country began to rise with the new Delta variant. This map shows considerably more of the country's counties in red and darker red, with red/dark red counties in every state and cases in urban areas reaching levels up to 291 cases.



Rural Differences

Maps 1 and 2 showed the changes in cases in counties across the U.S. Figure 4 shows these data for metropolitan, micropolitan, and noncore counties (OMB, 2017) to show the changes in cases and death rates between May 2 and August 8, 2021. While cases and deaths are rising across the country, we see the sharpest increases in urban areas where more facilities are located and people reside. While this looks optimistic for micropolitan and noncore counties, rural areas tend to lag behind, but catch up to urban centers in outbreak severity. In addition, [people in rural areas are disproportionately more likely to live in institutional settings](#) and more likely to experience disability compared to people in urban areas. Furthermore, rural settings are at risk of [experiencing shortages](#) in healthcare capacity to manage outbreaks.

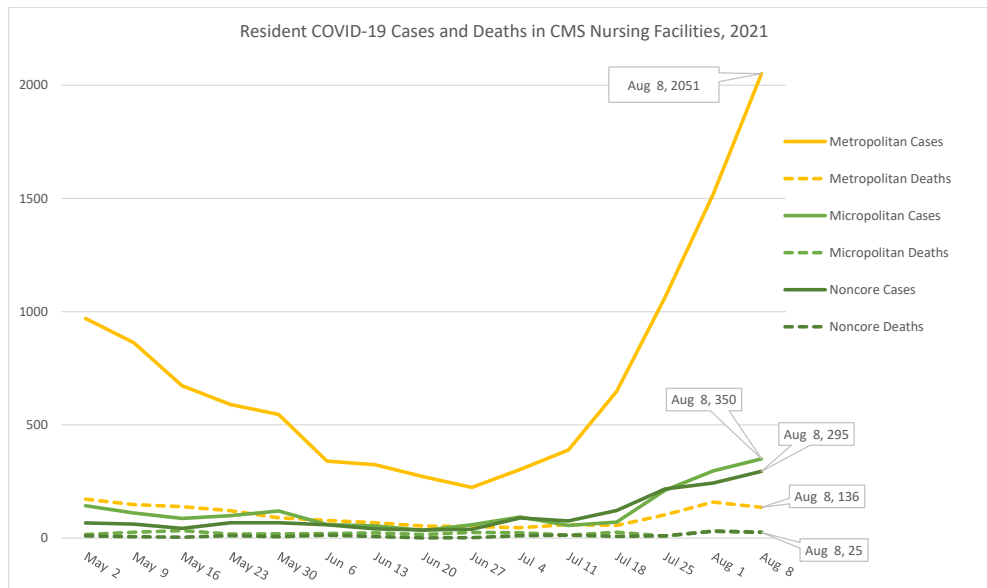


Figure 4: Resident COVID-19 Cases and Deaths in Nursing Facilities Rural/Urban

Regional Differences

Figure 5 shows regional differences in cases and death rates across the same time period. [Regions](#) are defined by the US Census Bureau. Outbreaks are particularly severe in the South, but the Midwest, Northeast and West are all showing increases in the number of reported cases. Currently, deaths remain low across all regions. Lower death rates could reflect the impact of the vaccine, suggesting that residents may be infected but experiencing milder reactions. Low death rates may also reflect a lag behind infection case rates. This phenomenon is just starting to show in the data, and may predict an increase in deaths in the coming weeks.

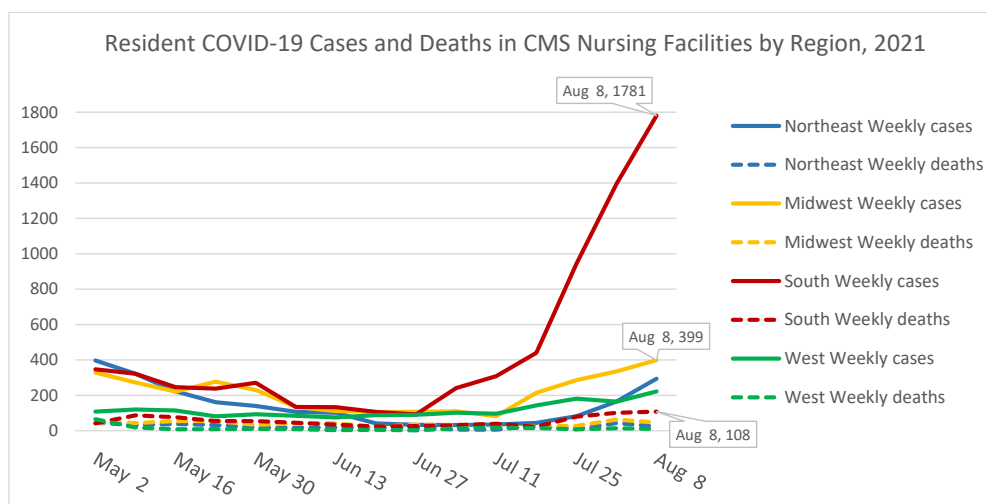


Figure 5: Resident COVID-19 Cases and Deaths in Nursing Facilities by Region

Rural Differences

Increasing Cases and Deaths

Rates of infection in nursing homes are [significantly higher](#) than in the general community. These increased rates of infection have led to increased deaths in these facilities, and represent [up to one third](#) of all COVID deaths in the United States. Despite this glaring disparity, people with COVID-19 continue to be discharged from hospitals and admitted into skilled nursing homes. It is concerning that disabled individuals, many of whom are at greater risk of infection and death are being admitted or readmitted into congregate care settings where the virus has proven very difficult to control.

Need for Increased Vaccination Rates

The data presented in this factsheet illustrate what is likely the beginning of a new wave of infection and death in skilled nursing homes across the United States. One of the best strategies we have to stop the pandemic is through vaccinations. However, while rates of resident vaccinations are high (82.8%) vaccination rates among staff in nursing homes appear to have stalled. Facilities across the country have failed to reach a critical threshold for keeping the virus at bay. Nationally, staff vaccination rates stand at 60.5%, but Southern and Midwest regions and rural counties report much lower rates of staff vaccination. Only the West is near the [industry target of 75%](#).

Low rates of vaccination, specifically among nursing home staff, is a likely driver of increasing cases and deaths. As outbreaks continue, the risk of breakthrough infections for vaccinated residents (and staff) increase. Recently, the Biden administration [announced](#) that it was developing emergency regulation mandating staff vaccinations across all CMS facilities. Current [requirements](#) for CMS workers that include education and vaccination for those who want it, have not demonstrated that voluntary vaccination is enough.

Recent findings about the length of [vaccine effectiveness](#) present additional concerns. Residents in skilled nursing homes were some of the first in the U.S. to receive COVID-19 vaccinations, starting in March 2020. However, a recent [CDC report](#) highlighted that the effectiveness of the Moderna and Pfizer vaccines dropped just as the Delta Variant was taking hold. The U.S. Federal Food and Drug Administration's (FDA)

approved [Pfizer-BioNTech's Biologics License Application to market its COVID-19 vaccination](#).

The FDA's full approval was based on scientific reviews of study results and data. Full FDA approval means that local, state and national emergency management may have new opportunities to use policy-level mitigation measures such as employer requirements for workers to be vaccinated that were not available or as readily implemented when the Pfizer-BioNTech's COVID-19 vaccination only had FDA Emergency Use Authorization.

Community-based Options

People with disabilities have options and don't need to reside in high-risk institutional settings. [Centers for Independent Living](#) across the country have been facilitating and coordinating [emergency relocation and transition programs](#). For instance, Roads to Freedom, a Center for Independent Living serving North Central Pennsylvania, has been actively working to transition people from institutions. Rather than dampen these efforts, COVID-19 highlighted why this work is so important.

As Misty Dion, Roads to Freedom's executive director states,

“Our transition services expanded to 33 counties in the Commonwealth and have successfully transitioned 54 consumers in 2020 and already transitioned 37 people into the community so far this year.

This is a remarkable feat during a pandemic which targeted people with disabilities living in congregate care settings. Our CIL is blessed with individuals dedicated to empowering people with disabilities to live full independent lives outside of unsafe, institutional settings.”

In addition, people with disabilities and disability-led organizations should be [at the forefront of community action](#) to address and mitigate the disproportionately negative effects of the pandemic.

Transition and emergency relocation efforts are effective public health strategies but lack funding

As [research](#) is demonstrating, people are safer in the community and is where people want to live. While the expansion of programs like [Money Follows the Person](#) and smaller programs through the [Administration on Community Living \(ACL\)](#) are a start, the consequences of not supporting transition and integration are dire in the midst of an ongoing pandemic.

Centers for Independent Living and other local collaborative efforts, such as the [Institutional Rescue and Recovery Coalition](#), are working tirelessly to save lives through local partnerships and community building.

Additionally, in order to live successful community-based lives, many disabled people need community-based services and supports. And yet, many of these programs have also been impacted by the pandemic. For example, a [state-level survey](#) conducted by Kaiser Family Foundation reported a decline in Home- and Community-Based Services (HCBS) provider infrastructure during the pandemic, which has exacerbated unmet needs for community based care. Individuals who want to live (and [have the right to live](#)) in the community, but can't access care, risk being institutionalized where they are at higher risk of infection and death from COVID-19.

Conclusion

COVID-19 cases and deaths are on the rise in nursing homes across the country, and vaccination rates amongst staff and residents have stalled. It's imperative to support community-based strategies and solutions to transition people with disabilities living in congregate settings into the community.

This factsheet is a product of the Research and Training Center on Disabilities in Rural Communities and Disability Data Advocates Taking Action (DisDATA). DisDATA is a cross-disability, national collaborative of people with disabilities, researchers, service providers, activists, and allies committed to making data about disability equitable, actionable, and transparent. If you are interested in learning more about or joining DisDATA please contact: disdata@mso.umt.edu.

If you have any questions about the data or content of this report contact Lillie Greiman at lillie.greiman@umontana.edu.

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Images

Unless otherwise noted, all photos are from Healthy Community Living (www.HealthyCommunityLiving.com) under which people from around the country have sent in photos of “Real People, Real Places” that have to do with living with disability in America.

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